

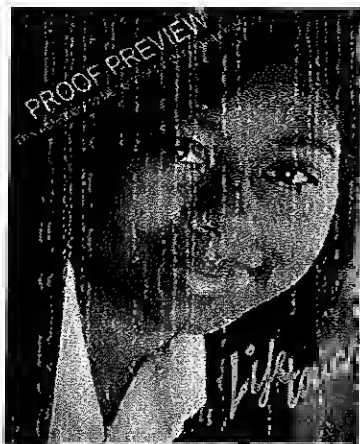
Testimony of Kimberly Castro

December 18, 2008

My name is Kimberly Castro and I am coping with the loss of my daughter, Chelsey Cruz. My story is one of betrayal and anguish. She was taken from me forceably by DCF, not because of my neglect or any wrongdoing on my part. We were played as pawns in a horrific game of control and greed which ultimately took her life. Our rights were taken away, violated. I was left with my hands tied, and her wishes were ignored. My story begins with Chelsey, who was a 15 year old, brilliant young lady who attended Capital Preparatory School. Chelsey was diagnosed with lupus when she was nine years old. She was brave, facing the many different procedures and treatments that they gave her. Up until the time she died, she had been used as a guinea pig, treated with experimental chemotherapy drugs such as cellcept, cytoxan, and countless others to manage her Lupus. These drugs did not benefit Chelsey in anyway, caused her kidneys to fail, and I wanted them to be discontinued immediately. They made her sick, left her drained and were never approved by the FDA to treat Lupus after several trials. When I disagreed with doctors in Connecticut, trying to explain that the medications were making her condition worsen, I requested alternate treatments and second opinions. They reported me to DCF with charges of medical neglect, but all allegations were unsubstantiated. We sought help from Boston Children's Medical Center, and at first, they agreed and began to wean her off the medications. She began to look and feel better. However, one fateful visit occurred when a chief doctor came on the scene. He demanded that Chelsey be put back on the experimental medications and threatened to call DCF if I resisted. I asked to seek a second opinion, and was immediately dismissed. My daughter was forcibly admitted and guards were placed outside the door, keeping me from my child. Massachusetts DSS and DCF in Connecticut worked to entrap us, and an Order of Temporary Custody was obtained in Boston. I was told by the Boston Dept. of Social Services that I was no longer able to make any medical decisions for Chelsey. I went to local newspapers with my story, sharing my pain in hope to gain justice. The law was not on our side, and months passed before my case came up in court. I struggled to find a lawyer who would adequately represent me and Chelsey. We were represented by court appointed lawyers who were not versed in litigating such a complex case, which left us vulnerable and improperly represented.

Chelsey was held in the hospital beyond medical necessity until they placed her with her grandfather. In the meantime I worked frantically, writing letters to DCF, the judge and Attorney General. Chelsey even pleaded with the judge in a letter stating how she "felt like she was going to die" on the medications and begged to "come home to her mother". But no one listened to Chelsey's cries for help. Sadly, Chelsey felt like she was imprisoned. She was, in fact, enslaved to the faulty system and agencies that truly do not seek to benefit the child or the family but to profit off of them. But that didn't stop me or Chelsey from speaking. We begged them to listen before something awful happened. Chelsey wanted to go to court to explain her concerns but was not allowed to, so she wrote a letter to the judge. Chelsey words, "I don't want to come to back to his hospital", "I don't want to take these medications any more" "What has to happen for you guys to listen"? "Do I have to die first for you to listen to me"? These words were ignored and the experimental medications were continued to be administered. Tragically, these were some her last words to the Doctors at Boston Children's Hospital and to her DCF worker just days before she died. She died without being shown justice, mercy or compassion. No investigations from the State Child Advocacy Commission were shared, no recourse from the judicial system that just dropped the case. But now I am here on her behalf to ensure that justice will prevail, and this will never happen to any parent, child or family again. My name is Kimberly Castro, and I am coping with the loss of my

daughter due to DCF corruption and dysfunction. This agency is not for children and families. It is for profit. Where is the accountability and responsibility? Why is it structured to be all-powerful? It is a virus that needs to be cured. (See Attached)



Dear Your Honor,

It was of great importance that I speak to you. Since I was denied the request to speak to you in person, I'm taking the opportunity to address my concerns about this matter.

The first thing I would like to mention is that I believe that this time that I have been separated from my family has taken an emotional toll on me. To be separated from the family I know and love, that have been my only true advocate and support was in no way beneficial to me because at a time like this is when I need my family the most. My parents have truly been there for me since the beginning and besides me, they know more about me than anyone else. They have been the only one that has been listening to how I feel about my illness and the effect of the treatments that I have been receiving. The conflict that I am having is that according to the law my parents are supposed to have the right to be making all decisions for my medical care.

Now if this is true and I have been telling my parents how I feel and they address my concerns to the doctors but the doctors ignore how the treatments are affecting my body and my life, as a result my parents are being penalized for voicing my concerns and respecting the fact that I do know how these treatments are affecting me and the everyday struggles I endure because of them. For example, since starting these treatments I'm very fatigue most of the time because of constant diarrhea. I used to have so much hair that I couldn't even put it into a ponytail and now it's so thin, that I can see my scalp. Not

to mention the infections that I get often due to my suppressed immune system that is caused by the prednisone and cellcept. Even though I have expressed to the doctors my concerns as well as I needed to be hospitalized because of the complications to these treatments they continue to keep giving them to me. It's as though they are ignoring me. They continue to force these treatments on me and they don't care what happens to me. I feel that without my parents who are my advocates, I now have no one to advocate for me properly.

In a few months I will be 16 years old and I feel that I am able to make a sound decision about the medical treatment and physician that I would like to choose. I feel that I have carefully thought about and weighed the pros and cons of the treatment for lupus. I have already tried what the doctors consider to be standard of care for the past 5 years. I have experienced the horrifying side effects of them and realized that they have not helped me in any way in fact I feel I have gotten worse and now require dialysis. In light of this, I no longer want to use them. The reason why I can say this is because I know that I have tried a lot of their recommended medications and treatments and they keep changing which means the doctors are still looking to try to see what will work. I have read about Dr Fuhrman and found he has successfully treated many lupus patients in fact he has treated a girl my age with lupus and end stage renal failure and she no longer has any evidence of lupus or renal disease. This gives me a lot of hope that he can help me to get better so I can go on living a normal life. I would also like to be back with my mom and brothers without any interference from any agency. I hope that you reading this letter gives you a better understanding of me and my situation and I'm optimistic that you will make the right decision.

Sincerely, Chelsey Cruz

11/14/07

To whom it may concern:

This letter is to inform you of what my position is in regards to my daughter Chelsey Cruz. First of all, I would like my daughter to be returned back to my care. I have done nothing wrong that would warrant her removal from my custody. With regards to her medical treatment, I find it to be very misleading that Dr Harmon claims I have refused all treatments and medications when Chelsey's medical file is extensive from all the different treatments they have tried. The medication regimen she is currently on is even longer from them trying everything under the sun on her. I brought Chelsey to these doctors to treat her lupus and renal failure. Not to be used as a guinea pig. I no longer want her to be treated with cytotoxic chemo drugs such as cellcept, cytoxan, rituximab, or Immuran to manage her Lupus. These drugs have not benefited Chelsey in anyway and I would like for them to be discontinued immediately. Nor, have they been FDA approved to treat Lupus after several trials. I am requesting that the only treatment to be used to manage Chelsey's Lupus would be prednisone at this time. Oral prednisone and pulse steroids as needed. I do not have a problem with the use of epogen as needed. However, I do have a problem with the misuse of the epogen there needs to be a guideline for the right time and dosage being used and it needs to be explained to me in detail. The reason why I am very concerned about this drug is because there has been episodes of Chelsey developing blood clots. In addition to the new discovery of antiphospholipids being detected in Chelsey's blood labs. She has never struggled with this condition in the past. Not to mention the strict warning label on the box and all over FDA websites about the anemia alert along with blood clots. I find it very alarming that doctors are prescribing a drug epogen that causes anemia and bone marrow suppression which causes her body not to produce red blood cells. For what they claim is needed to control anemia. I have spoken to other renal patients adults and teenagers who do not have Lupus and they have stated that they are not on a continuous dose of epogen. They only use it periodically as needed. Chelsey is on it every day and in high doses. That is why I don't want her on any chemotherapy for the treatment of her lupus. Because I know this is the reason for the use of high doses of procrit. Plaquenil is the newest drug just added to Chelsey's regimen 10/31/07 hospitalization to manage her Lupus which is a milder form of treatment for lupus of which I have thoroughly investigated and I am insulted by the offering of this drug now. Because it is usually one of the first treatments used for a patient presenting with Lupus. It is for Lupus patients who present with aching joints and inflammation and rashes which Chelsey has never had problems with since initial diagnosis of lupus back in 2002.

As for all the rest of her medications such as dialysis I know with out a shadow of a doubt is the most important treatment needed to preserve her life. Her calcitrol, levoxyl, protonix, renavite, iron, and renagel are all fine for her to take because these are only vitamins and antacids.

CC Clarissa Lebron Supervisor @ Dept of Children and Families

Atty Michael Perez

Dr. William Harmon Chief Nephrologist@ Boston Children Medical Center

Dr Nancy Rodig Nephrologist @Boston Childrens Medical Center

Dr Sundel/ Chief Rheumatologist & Rheumatology Doctors @ Boston Childrens Medical Center

Attorney General Richard Blumenthal

Hilary Waldmen staff writer @ Hartford Courant

FIERCEST OF LOVES

**AS A MOM DISPUTES TREATMENT OF HER DAUGHTER'S LUPUS, DOCTORS CRY
NEGLECT. JUVENILE COURT IS THE NEXT ARENA.**

Hartford Courant - Hartford, Conn.

Author: HILARY WALDMAN

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Kimberly Castro loves her daughter.

But doctors at three hospitals say the East Hartford mother is endangering her life.

For the last five years, the 35-year-old mother of three has immersed herself in her daughter's lupus diagnosis, reading every prescription insert and using her home computer to research every medication.

And, for Castro, it all adds up to a clear conclusion: The powerful chemotherapy and immune-suppressing agents prescribed at Children's Hospital in Boston, Yale Children's Hospital and Connecticut Children's Medical Center have destroyed her daughter's kidneys. The side effects from these and other powerful drugs, she believes, are threatening the 15-year-old's life.

Castro wants her daughter, Chelsey Cruz, off the drugs and has already fired three teams of doctors because they disagree with her.

"Everything that they're giving me to put into my daughter's body is toxic," she said. "I've done my homework. I've checked every medication."

But the doctors — including one of the world's experts in childhood kidney disease — contend that without the drugs and an eventual kidney transplant, Chelsey could die.

Doctors at all three hospitals have accused Castro of medical neglect. By the time Chelsey was hospitalized at Children's Hospital in Boston last summer, a uniformed guard had been posted outside her door.

Now, the state Department of Children and Families has taken temporary custody of the girl, claiming that while Castro's battles with the doctors may be well intentioned, the mother may be guilty of loving her daughter to death.

Castro and Chelsey's father, Eliezer Cruz, have been summoned to Superior Court in Hartford to argue that they should be allowed to regain custody of their daughter, now staying with a relative who has agreed to follow the doctor's orders.

A trial is scheduled to begin in November in juvenile court, but legal experts say the case could drag on for months while the judge tries to unravel the tangled web of child welfare laws that sometimes pits parental rights against the state's obligation to protect children.

"It's a highly personal judgment when you have a loving and caring parent and a 15-year-old who agrees with what the parent is doing," said Paul Chill, associate dean of academic affairs at UConn Law School and an expert on child protection issues.

"But I think most courts will side with the experts."

Beyond the legal issues, the case offers a rare glimpse into how the new frontier of Internet research can empower patients as never before, but could also arm untrained people with information that, unfiltered, could lead to mistaken conclusions and medical battles.

Do No Harm

Castro says she is being forced into an untenable choice between losing her only daughter to overly aggressive treatment and losing her child to the state.

"Our position is parents have the right to choose medical care for a child that they think is proper," said Michael Perez, Castro's court-appointed lawyer. "It is embedded in the U.S. Constitution and the Connecticut Constitution: Parents have a right to make decisions about their children, especially medical care."

But Castro's conclusion, according to doctors familiar with Chelsey's case, is incorrect.

"Ms. Castro objects to some or all of the treatments that we propose and outlines multiple complications that she feels Chelsey has suffered because of the medications," wrote Dr. William Harmon, director of pediatric nephrology and chief of the transplant program at Boston Children's Hospital.

The problem, say the doctors, is that Castro is seeing only the complications without understanding the potential benefits -- namely, that the medications Chelsey is taking are keeping her lupus at bay, perhaps even keeping her alive. Moreover, they say, there is no evidence that the drug Castro objects to most, Cytoxan, causes kidney failure.

The mercurial nature of Chelsey's illness complicates the debate.

Systemic lupus erythematosus can affect different people in very different ways. The disease occurs when the immune system mistakenly attacks the body's healthy tissue. The attacks are unpredictable, with milder forms affecting the skin and joints and severe forms targeting crucial organs such as the kidneys, heart, brain and lungs.

Adding to the intrigue, lupus can virtually destroy the kidneys before the patient even recognizes any symptoms.

Chelsey's ordeal began in the spring of 2002, just about a month before her 10th birthday. Then a fourth-grader at Mayberry Elementary School in East Hartford, Chelsey was bothered by night sweats and occasional fevers. She complained of muscle soreness and achy joints. Suspecting lupus, her pediatrician referred her to Dr. Larry Zemel, a rheumatologist at Connecticut Children's Medical Center.

Zemel declined to be interviewed for this story. But according to his notes in Chelsey's medical chart provided by Castro, his examination confirmed the pediatrician's suspicions, and he admitted Chelsey to the hospital the following day. Urine tests showed high levels of proteins and red and white blood cells -- indicators that Chelsey's kidneys were already damaged.

A nephrologist said Chelsey's urine tests indicated she was suffering from the most severe form of lupus nephritis -- a condition in which the immune system attacks the kidneys. He prescribed steroids and an immediate intravenous infusion of Cytoxan, a drug approved for cancer treatment that has shown promise in stopping or slowing immune system attacks in lupus patients.

By autumn, a visiting nurse was administering Chelsey's Cytoxan at home, and she entered fifth grade in a program for gifted and talented children at a nearby magnet school. For a while, Castro thought her daughter was lucky to be offered such "a miracle treatment" when adults she knew with lupus struggled with the side effects of more traditional steroid treatments.

But Chelsey was not getting better. During the first year of her treatment, she was in and out of the emergency room 23 times.

By the summer, Castro was beginning to do her own research and having doubts about the quality of her daughter's care.

She feared the miracle drug was actually destroying her daughter's kidneys.

Mom Vs. Docs

Castro was in the process of transferring Chelsey to Yale Children's Hospital in New Haven when the girl doubled over with excruciating abdominal pain.

In the Yale intensive care unit, doctors told Castro that Chelsey's kidneys had shut down. Castro was furious.

Doctors at Yale started kidney dialysis. Chelsey continued to miss school, sick with vomiting, diarrhea, dehydration and electrolyte imbalances. Castro insisted it was caused by the medicine.

The doctors said Castro was not properly supervising Chelsey's home dialysis.

Friction was mounting.

Responding to Castro's concerns, doctors at Yale switched Chelsey's medication from Cytoxan to Cellcept, a newer class of drug that suppresses the immune system.

When Chelsey became riddled with infections, Castro quit her job with an advocacy group for people with intellectual disabilities and devoted her time to researching Chelsey's disease and caring for her two younger sons. After reading everything she could find on the Internet by Googling "lupus and medication," Castro said no more Cellcept.

Chelsey's doctor, Castro recalled, banged her hand on the table and said, "That's it." The doctor called the state Department of Children and Families, and the state opened an investigation into charges of medical neglect.

Concluding that "Mrs. Castro seems to have suffered a great loss of trust with those attempting to provide appropriate treatment for Chelsey," the state declined to act on the allegations. As a compromise, DCF and Castro agreed to transfer Chelsey's care to Children's Hospital in Boston.

But it wasn't long before the same fight Castro had at Connecticut Children's and at Yale broke out again in Boston.

Harmon, considered one of the world's leading experts in childhood kidney failure, promised to prepare Chelsey for a kidney transplant by putting her lupus into remission with Cellcept and Cytoxan.

Castro said no.

"I said you guys don't know what the hell you're doing, you're experimenting on kids, you're killing kids and I'm going to expose you," Castro recalled shouting at Harmon.

State Steps In

Castro acknowledges that maybe she's been a little too combative with the doctors.

Maybe she's raised her voice a little too loud or not shown enough deference. It was probably a mistake, she says in retrospect, to accuse the doctors of being legal drug peddlers. But what do they expect? Nobody, she says, is listening to her.

She also insists that some of her outbursts have turned out to be justified.

Once, she recalled, Chelsey's dialysis port ruptured, resulting in emergency surgery because doctors at Yale ignored her concerns about a lump near the port site. So when Chelsey developed a similar lump in Boston, Castro dug in her heels, demanding an ultrasound before dialysis. The doctors called her "belligerent."

"I want to decide what kind of treatment I want for my daughter," says Castro, who is separated from Cruz and supports herself and the three children by providing respite care in her home for troubled children and for children with intellectual disabilities. "I don't trust them anymore."

In August, Harmon made a report to Massachusetts child welfare authorities, charging medical neglect on Castro's part, and the charges stuck.

An order of protection was signed in Massachusetts on Aug. 27. Until this month, Chelsey was held at Children's Hospital of Boston with a uniformed guard outside her door.

This month, the case was transferred to the Connecticut Department of Children and Families, because the family lives here.

And last week, Chelsey was discharged to her grandfather's house, where she continues to get dialysis, Cellcept and a host of other medications, a compromise while the state tries to determine whether her mother should get her back.

Grandpa's House

Castro says she realizes her high school equivalency diploma does not look like much against a collection of M.D.'s. But she says she has the gut wisdom that only a mother can bring to her child's care.

That, she says, has to count for something.

And therein lies the core of the upcoming court case and the rare others like it that challenge the courts by asking how far a parent must go to warrant taking a child away.

The answer is not clear.

In a written statement, DCF officials said the department goes to great lengths to prevent removals wherever possible.

"However," the statement continued, "when medical experts are in agreement that a course of treatment is necessary to avoid severe, potentially life-threatening or life-altering consequences, it is the department's responsibility to rely on the professionals ... so that the most sound judgments can be made about the care of vulnerable and often fragile children."

But the law does not specifically give more weight to the opinions of parents or the medical establishment, said Carolyn Signorelli, the state's chief child protection attorney. And the terms "neglect" and "best interest" of the child are not well defined.

"So, you get into a situation where others are making their own assessment regarding those decisions," Signorelli said.

In the meantime, Chelsey says she loves her grandfather and feels comfortable in his house in a neat middle class subdivision in East Hartford.

But she'd rather be home with her mother and brothers in the two-family home they share on the other side of town. And she says she feels hurt when she hears Castro accused of being a bad mother. Just the opposite is true, Chelsey says.

"I feel kind of angry that I'm not home with my mom right now," says Chelsea, whose petite frame, rectangular metal-rim glasses and mane of dark curls make her look more like a little girl than a teenager.

"I never thought this would happen."

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Abstract (Document Summary)

A trial is scheduled to begin in November in juvenile court, but legal experts say the case could drag on for months while the judge tries to unravel the tangled web of child welfare laws that sometimes pits parental rights against the state's obligation to protect children.

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GIRL IN MEDICAL DISPUTE DIES

LUPUS TREATMENT PITTED MOTHER, STATE

Hartford Courant - Hartford, Conn.

Author: HILARY WALDMAN; COLIN POITRAS

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Chelsey Cruz, a 15-year-old who ended up at the center of a custody battle between her mother and the state that left each side accusing the other of harming her, died suddenly Tuesday.

The state Department of Children and Families last August filed charges of medical neglect against the girl's mother, Kimberly Castro, and took custody of the East Hartford teenager.

Castro had disagreed with three teams of doctors who treated Chelsey for lupus.

DCF stepped in following a complaint by child welfare authorities in Massachusetts. Chelsey at the time was being treated at Children's Hospital Boston.

Doctors from Connecticut Children's Medical Center in Hartford and Yale-New Haven Children's Hospital had filed complaints with Connecticut authorities, contending that Kimberly Castro was hurting her daughter by objecting to the treatment they recommended. Those charges did not stick.

After the Boston complaint, however, DCF placed Chelsey in the custody of her grandfather, who agreed to follow the doctor's orders. Both sides were awaiting a final ruling in the case when Chelsey died.

In an interview last autumn, Chelsey, an honors student, said she felt her mother was acting in her best interest. She said her biggest wish was to go home and be healthy.

"I feel kind of angry that I'm not able to be with my mom right now," Chelsey said in October.

Michael Perez, Castro's court-appointed lawyer, said Chelsey was taken to Connecticut Children's Medical Center Tuesday morning and probably died of cardiac arrest caused by sepsis, an overwhelming infection that can shut down the body's organ systems very rapidly. Perez said an autopsy is planned to determine the exact cause of death.

Perez said he last saw Chelsey in January at her grandfather's house and she was talkative and well enough to do dishes and join a conversation at the kitchen table. Although she continued to travel to Boston for treatment, she finally felt strong enough to return to school at Capital Prep Magnet School in Hartford, he said.

"The whole thing is just a huge shock to us all," Perez said.

The dispute over Chelsey's care began almost six years ago, when doctors at Connecticut Children's Medical Center diagnosed the girl with lupus, a disease in which the immune system mistakenly attacks the body's healthy tissue. The attacks can be unpredictable, with milder forms affecting the skin and joints and more severe forms targeting crucial organs such as the kidneys, heart, brain and lungs.

Chelsey, her doctors said, had a serious complication called lupus nephritis, which can cause devastating kidney damage. They prescribed steroids and an immediate intravenous infusion of Cytoxan, a drug approved for cancer treatment that has shown promise in stopping or slowing immune system attacks in lupus patients.

When Chelsey continued to be wracked by complications, including abdominal pain and diarrhea, her mother lost faith in the doctors at Connecticut Children's Medical Center. Castro transferred Chelsey to Yale-New Haven Children's Hospital. There, the doctors found that Chelsey's kidneys had failed.

They blamed the lupus, but Kimberly Castro blamed the medication.

At Castro's request, the Yale doctors switched Chelsey to a newer form of treatment. But that, too, caused serious side effects and Castro objected to that, too. That's when Yale called DCF, accusing the mother of medical neglect.

After an investigation, DCF determined that Castro simply no longer trusted the doctors. As a compromise, DCF and Castro agreed that Chelsey's care be transferred to Children's Hospital Boston.

But it wasn't long before the same fight Castro had at Connecticut Children's and Yale broke out in Boston. Castro did not want any more Cytosan or the alternative drug, Cellcept. The drugs, she said, were killing her daughter.

After a lot of angry back-and-forth, an order of protection was signed in Massachusetts in late August. Until Chelsey was returned to her grandfather's home in East Hartford, a uniformed guard was posted outside her room in Boston to prevent Castro from taking her daughter out of the hospital.

Perez said Tuesday that he and Castro plan to collect Chelsea's medical records. Castro has not yet decided whether she may take legal action against the state, he said. For the moment, Perez said, Castro is grieving.

Perez said a Superior Court trial on the medical neglect charges had just concluded in February and that Castro was awaiting a ruling. And he said, she remains convinced that the strong medications were too much for her daughter.

"Ms. Castro strongly believes there is a connection between the drugs that were being used and the results today," Perez said.

In a statement, officials at the Connecticut Department of Children and Families expressed sadness about Chelsey's death.

"The young girl had a variety of medical complications and Department staff did everything possible to ensure that she got the best medical care," the statement said. "The department extends its deepest condolences to the girl's family."

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Abstract (Document Summary)

The dispute over Chelsey's care began almost six years ago, when doctors at Connecticut Children's Medical Center diagnosed the girl with lupus, a disease in which the immune system mistakenly attacks the body's healthy tissue.

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MOTHER'S RAGE LIVES ON

A 15-YEAR-OLD EAST HARTFORD GIRL WITH LUPUS DIES, AND THE STATE OFFERS ITS SYMPATHY TO THE FAMILY, WHILE DEFENDING ITS ROLE IN THE WRENCHING CASE

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When Kimberly Castro buries her only daughter next week, she'll do so with a clear conscience, but with fury in her heart.

The state, she said, robbed her of precious time with her child, simply because she wanted control over the girl's treatment for lupus.

"I'm angry; I'm enraged right now," said Castro, surrounded by her family in her father's East Hartford home as she made funeral arrangements for her 15-year-old, Chelsey Cruz.

"Even if lupus would kill her, why take her away from me and not let me spend the last days with my child?" Castro said through tears Friday. "They ripped her away from me. I was the best mother to my daughter."

The state Department of Children and Families expressed sympathy for the family but defended its procedures in the case. DCF charged Castro with medical neglect and took custody of Chelsey last August after Castro disagreed with three teams of doctors about how best to treat the girl's lupus. While Castro said the strong medications prescribed by doctors were hurting Chelsey, the doctors said they were her best chance to survive.

When the girl died unexpectedly Tuesday in the emergency room at Connecticut Children's Medical Center in Hartford, she was in the temporary custody of her grandfather. The family was awaiting a ruling from a family court judge about whether the girl could go home.

In a letter to the judge dated Feb. 1, Chelsey, an honors student at Capital Prep Magnet School in Hartford, wrote about the "horifying side effects" of her medication and said her parents were being "penalized" for supporting her desire to try alternative treatment.

"I have already tried what the doctors consider to be the standard of care for the past five years. I have experienced the horrifying side effects of them and realized that they have not helped me in any way. In fact, I feel I have gotten worse and now require dialysis," Chelsey wrote. "In light of this, I no longer want to use them."

"I would also like to be back with my mom and brothers without any interference from any agency," she wrote.

Although it will not change anything, Castro said she would still like to get a ruling. DCF officials said in a prepared statement Friday that they were still unsure of how the case would end, in light of Chelsey's death.

"Department staff worked diligently to support the family and to ensure that the child's medical needs were met," DCF said. "The same staff sought to have mother engage necessary treatments for the girl that were recommended by doctors from three major hospitals. Our staff feel a great loss from the child's passing and deeply regret the pain experienced by her family."

Although Castro objected to her daughter's recommended treatment almost since the girl was diagnosed with lupus six years ago, the conflict came to a head last summer when Chelsey was hospitalized at Children's Hospital Boston.

Her kidneys had failed, and she was on dialysis. Doctors who previously had treated her at Connecticut Children's Medical Center and Yale-New Haven Children's Hospital said lupus, a disease in which the immune system goes awry and attacks the body's healthy organs, caused the damage.

They thought her best chance would come from two powerful chemotherapy drugs - Cytoxan and Cellcept - but Castro felt the medications were destroying Chelsey's kidneys. She fired the Connecticut doctors, who filed complaints against her. Eventually, Castro agreed to seek care in Boston.

There, Dr. William Harmon, director of pediatric nephrology and a renowned expert in kidney transplant for children, recommended that Chelsey continue on Cellcept. In court papers, he said he hoped to bring the lupus under control with the medication, then prepare Chelsey for a kidney transplant.

But Castro said the side effects from the medication were too much. Chelsey suffered with chronic intestinal distress and regular infections. Castro said the medication was doing more harm than good and ordered the doctors to stop.

In August, Harmon called in Massachusetts child welfare authorities, accusing Castro of medical neglect. He had a uniformed guard posted outside of Chelsey's hospital room to prevent Castro's possibly taking her daughter out of the hospital.

In October, when Chelsey was well enough to go home, the case was transferred to the Connecticut Department of Children and Families, and Chelsey was placed in the custody of her grandfather, who agreed to follow the doctor's orders. A hearing was called to reach a final decision. On Feb. 4, the trial wrapped up in Superior Court in Hartford.

Castro last saw her daughter Monday evening, during a supervised visit at Castro's father's house. She said Chelsey had been bothered by vomiting and diarrhea and was taking antibiotics for an infection.

After Castro returned home that evening, Chelsey cellphoned her mother many times during the night, crying because she was so sick.

The next morning, Chelsey's grandfather rushed her to the hospital. By the time Castro arrived, emergency room workers were trying to revive the girl.

Castro never saw her alive again.

"When I got there they were working on her," Castro said. She said she is not sure whether she will pursue further legal action.

"What does it really matter?" said an exhausted Castro Friday. "None of it is going to bring my daughter back."

Castro said doctors at the hospital told her that Chelsey died of heart failure caused by sepsis, an overwhelming infection that can attack the body's organs very quickly. But an autopsy report concluded that she died of kidney failure and lupus, according to the Office of the Chief Medical Examiner.

A funeral for Chelsey Cruz is scheduled for Tuesday at 10 a.m. at the Newkirk and Whitney Funeral Home in East Hartford. At Castro's request, the state Department of Children and Families is footing the bill.

"They owe it to Chelsey to pay for everything because the time she had left, they took away," Castro said. "I told [DCF] that this would happen. I warned them.

"And they never listened."

Castro said she will never believe that her daughter died of lupus or kidney failure. "I'm 100 percent sure that my daughter died of adverse side effects of the drug called Cellcept," Castro said. "Regardless of that, they had no right to force her to take a drug she didn't want."

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Abstract (Document Summary)

In a letter to the judge dated Feb. 1, Chelsey, an honors student at Capital Prep Magnet School in Hartford, wrote about the "horrifying side effects" of her medication and said her parents were being "penalized" for supporting her desire to try alternative treatment. Doctors who previously had treated her at Connecticut Children's Medical Center and Yale-New Haven Children's Hospital said lupus, a disease in which the immune system goes awry and attacks the body's healthy organs, caused the damage.

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